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AS ABILITIES CHANGE

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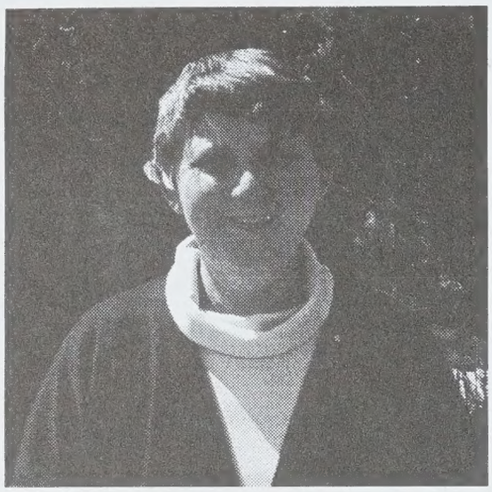
EDITORIAL

Communication, NOT Technology is What Counts

SHIRLEY McNAUGHTON



Shirley McNaughton

Peter has retired! From his full-time position as a professor at the Ontario Institute for Studies in Education (OISE), University of Toronto, that is! Not from **Communicating Together**! As you will see in reading this issue, he has increased his involvement in our magazine by taking on two of the roles previously undertaken by Rob Haaf — Associate Editor of our *Using Technology* section and Webmaster of **ComTog Online.** All the associate editors join me in congratulating him on his contribution over the years. He has given much, not only to OISE and its graduate students, but to the many community organizations in Toronto where he has volunteered his expertise generously, and to the international AAC community. His activities within the International Society for Augmentative and Alternative Communication, (ISAAC) ranged from organizing international conferences and research symposia to implementing the computerization of the ISAAC secretariat. We don't begin to know all the ways in which Peter helped others, but we do know and appreciate what he has done and continues to do for AAC users and professionals. We wish him many more years of enjoyment and exciting involvement in projects of his own choosing! As someone with ten years of "retirement" experience, I welcome Peter to this next exciting life stage. In this first issue of **Communicating Together** since his official retirement, you will see that his article reflects one of the areas to which he hopes to devote some of his time — providing practical information about computer technology.

Before commenting on some of the changes you will see in the coming year of **Communicating Together**, I would like to share some of my thoughts regarding our theme — *Communication, NOT Technology is What Counts*. For three decades, I have had a love-hate relationship with technology, or perhaps it could be best described as a vision-frustration relationship! I have worked countless hours with programmers and technicians seeking to achieve the wonderful benefits possible through technology and I have shared in the exhilaration of many breakthroughs. Yet this has always been balanced by disappointment at the huge amount of time required of individual AAC users in order to adapt their way of functioning (both cognitively and physically) in order to interface with and have control over a new piece of technology, be it hardware or software. Several of my former students describe themselves (affectionately) as guinea pigs. And with good reason. Through their growing years, and even today as adults, they are involved as "subjects" in developmental and experimental projects, from which much is learned regarding technology. The results in the form of robust applied technology is not always evident, however, to those who served as the guinea pigs. AAC users are still subjected to long waits for assessment, many hours of practice to master new devices, technical breakdowns, and always the knowledge that there will be new learning expectations placed upon them in the future as technology undergoes further changes.

No matter how current the technology, it places high demands on those with severe speech and physical impairments, especially those who do not have fluent literacy skills. I still look back fondly to the device called the Autocom, developed at the Trace Centre, Madison, Wisconsin, in the seventies by a team of university students working with Gregg Vanderheiden. The principle behind its design was that of technology *adapting to the person* rather than that of requiring the *person to adapt to the device*.

Before leaving this topic, I must say a word about the developers, producers and distributors of AAC technology. As ISAAC's founding president I worked hard for their inclusion within the organization, as

I saw them as critical members of the team. I believe we are still striving to find the right balance among all those who are involved in delivering technological service to AAC users. The more all players involved in the provision of technology can share their knowledge and work together, the better will be the situation for AAC users. I have appreciated very much over the years, the contribution made by manufacturers to the field of AAC. My one regret is that they must focus their production on models that can be used by those populations with the larger numbers. The needs of those individuals whose numbers are smaller, and who have severe and multiple impairments often must be met by volunteers developing one-of-a-kind devices.

Overall, I have seen technology dramatically improve the lives of many AAC users. I have, however, also known many individuals who have devoted countless hours of effort, and yet experienced great frustration due to the minimal long-term results. Always they must cope with changing technology or too large a gap existing between the requirements of the technology and the capabilities of the individual.

Given my long-standing ambivalent attitude toward technology, it was very interesting to me, at our 1999 Associate Editor meeting to hear concerned technology appraisals by adult AAC users and those who work with them that reinforced my observations over the years. The theme for this issue came from the associate editors — *Communication, Not Technology is What Counts*!

I hope this issue of **Communicating Together** will be of particular interest to those AAC users who are having difficulties with technology. They can know that they are not alone. Hopefully they will share their experiences with our associate editors for inclusion in future issues. To the manufacturers and distributors of AAC technology, we need to say how much we appreciate the work that they do — and at the same time remind them that their continued efforts are greatly needed. There is still a long road to travel before every AAC user has the technology to meet his or her communication needs. And, after all, it is the communication that counts.

The Associate Editor meeting brought several changes. We were sad to learn that both Geb Verburg and Rob Haaf needed to take leaves of absence for the next year. Both of them have very heavy work loads and felt they could not give sufficient time to **Communicating Together**. We will miss them!

We were able to welcome two new associate editors — George Pigache, who will be editing a section called *Controversies* and Jim Stuart who will manage our *Poet's Corner*. We look forward to their involvement.

There were other changes as well, as we renamed some of our sections and welcomed Tracy Shepherd back from maternity leave. Tracy's section will be called *Clinically Speaking*, Nola Millin's section will be called *Reflections*, Suzanne Clancy will be writing *What Now?* and Paul Marshall is changing his *Paul's Place* to *Paul's Pulpit*. You will see why when you read his section!

Alda Stepran's section remains *As Communication Changes*. Alda will be sharing it with Jim Stuart. My *SymbolTalk* maintains its same title and will appear in future issues from time to time. We hope you enjoy the new sections and new perspectives that will be appearing in the coming year.

Our feature article for this issue was submitted from Scotland. We were delighted to receive such an excellent blending of the two topics that comprise our theme. It offers a prime example of a communication issue combined with a technical one, where we hope the communication priority wins out! It also presents an informative format that clearly demonstrates the collaborative nature of the writing. We know Norman Alm and Kate Ellis would enjoy hearing the reactions of readers to their article. We will be pleased to forward your thoughts to them.

We want to share our themes for the next three issues. For the Fall, 1999 issue, the theme is *The Caregiver*. For the Winter, 2000 issue, *Why become independent and how to do it*? and for the Spring, 2000 issue, *The right to dream*!

Remember, we invite your articles and poems as they relate to our upcoming themes. Your correspondence can be sent directly to the appropriate Associate Editor or in care of **Communicating Together**.

Lastly, we have a correction to make to our Spring issue. On page 15, Scott McArthur, Director of Training at the Ontario Federation for Cerebral Palsy, was referred to as an AAC user. While we know Scott would be an exceptional AAC user if it were necessary for him to use a voice output device, his speech is very well understood. The term was used inappropriately and in error. We apologize.

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Computer-Assisted Swearing

NORMAN ALM & KATE ELLIS

Norman Alm & Kate Ellis

Swearing is an important, powerful, and widespread form of communication that is difficult for AAC users to perform, for a number of social and technical reasons. This article outlines these reasons, from an historical, a sociolinguistic, and a personal perspective. The nature of swearing as a form of 'word magic' makes it a difficult subject to discuss rationally, even in an article such as this one. We argue that the social barriers outlined need to be addressed through honesty and courage, and technical barriers need to be overcome through ingenuity.

From Norman Alm

I am a researcher based at Dundee University in Scotland. One of my research interests is investigating ways of improving AAC systems. I am also interested generally in the nature of conversation, and in a computer based system as an element in a communicational situation. Kate and I met originally at ISAAC meetings. She gave a presentation at the Dublin conference last year about her experiences with swearing using an AAC system. Over coffee I suggested we should produce a joint article that put her experiences into the historical and social context of swearing. We worked on the paper over the next few months and this is the result.

From Kate Ellis

I am in my thirties. I have two brothers and one sister. One is older and two are younger. We four see quite a lot of each other. I attend a drop-in centre in Stirling four times a week which I enjoy very much. They do all sorts of different things, like going shopping or having nights out and things like that. I like to be kept busy because I feel I can handle mysef better. I feel when I am involved with things I am in my element. People can handle me better if I have things to do. If, on the other hand, things are in a lull, that's when I can't handle myself very well. I use a Liberator to talk to people. I go to conferences all over the world and am also involved in helping children with cerebral palsy and learning difficulties at a high school in Stirling. I enjoy helping out because it gives me a sense of satisfaction.

Introduction

In this article, we are not going to quote too many swear words and four-letter words. Instead, we will abbreviate. Such is the power of these words that we do not want to divert attention from the points we are making by creating an unsought emotional response in the reader. This, in itself, illustrates one of the points we want to make about swear words. They have the characteristic that they can affect those who hear them in a vivid way. So handling these words in an article such as this is a bit like handling explosives. It is to be done carefully. An article on explosives should not itself explode!

The starting point for this article was a presentation on the subject by Kate Ellis, who is an AAC user, at the ISAAC Conference in Dublin. The present article was built on this foundation and created with Norman Alm, a researcher, contributing the theoretical and historical structure and Kate providing ideas, insights and examples from her own experience. Kate's personal illustrations are given in italics throughout the article.

What is swearing ?

Swearing is the use of 'strong' language, language which has the ability to shock, amuse, or hurt others. Swearing derives its power from the use of words which are in some sense forbidden. The breaking of the taboo involved in using them gives power to the utterance. Swear words can be words with religious significance, words that refer to sexual or excretory body functions, and words that are insulting references to other racial or national groups and Swearing is "Language in its most highly charged state, related in this way to spells, charms, and curses — all forms of 'word magic' (Hughes, 1991, p.4). *Word magic* is using

words to gain power over the environment, or over other people. Swearing is not usually this specific in its intended effect, but it is a form of using words to create a powerful effect, or to powerfully influence others.

In English-speaking culture, most people will swear at some times. But interestingly, not all cultures swear. Japanese, Polynesian, native Americans, and Malaysian cultures have very little or no swearing. When a Japanese person hits his thumb with a hammer an expletive certainly comes out, but it is the equivalent of "Ouch!" It would seem peculiar to a Japanese person to call upon the Deity to consign the hammer to hell, or to shout out a word that had to do with excretion or sex.

On the other hand English-speaking people have for a long time had the reputation of being big swearers. In the 15th Century, the French nickname for the English soldiers was 'The Goddams'. We will be concentrating in this article on swearing in English. Many of the observations, however, will apply to other cultures which use swearing, with differences of emphasis and approach. Our chief historical and sociological references are the excellent studies by Montagu in 1967 and Hughes in 1991.

The attitude to swearing in English-speaking society is always undergoing change. In medieval times, to judge from the literature produced, swearing was done quite openly. It seems that from about the middle of the 18th century swearing began to be suppressed, in public that is. In private it has always flourished, even during the outwardly very prudish Victorian period.

In this century we have seen a gradual erosion of the swearing taboo. Books and films now contain a great deal of swearing. Television and radio programmes remain more restricted in the language which is allowed, because they go into so many homes and individuals have less opportunity to know what to expect before they see or hear it.

Hughes points out that "People swear by what is most potent to them" (Hughes, 1991, p.249). In the past, swear words were taken from the religious world, but with the increasing secularisation of western society, swearing has tended to move from religious to sexual, excretory, and racial/national themes. There has also been a change from swearing by to swearing at. Swearing in the form of taking an oath is less common now, and swearing in the form of delivering a curse or making one's language more vivid is the commonest current form.

If we examine swearing as a speech act, it is clear that it can perform a number of differing purposes. It can be used to let off steam, to give expression to pent up feeling.

Kate comments :

Everybody swears sometimes, when they are angry about something or having a bad day. I know people at the University who swear because they wouldn't be human if they didn't. It is used to alleviate stress. Everybody does it sometimes in their life.

When I am out in the car with my Dad, he comes out with some things that aren't repeatable. He calls some of the other drivers everything!

There is a playing field over the road from where I live and men play football there at the weekends. I have been over to watch them and they can come out with a few choice words as well.

Going a bit further than just letting off steam, swearing can be used as a means of being aggressive towards other people. This is one of the main reasons that swearing in public can create discomfort in people who overhear it. It is difficult to tell without knowing the speakers and the context whether it is just banter or whether a serious confrontation is not far off.

Kate comments :

I know I do swear because some people get on my nerves at times. But I swear because I get frustrated with certain people who think they know it all, when in fact they don't. This gets up my nose and my feelings. I can get angry, frustrated and can swear. I am just like everybody else — I have my moments.

I used to go to a day centre. One day visitors came around to the centre. I had my computer in front of me and was minding my own business, when this person started talking to me as if I didn't understand. So I told the person to 'bugger off' and the staff were trying to keep straight faces. After the visitors went away, the staff were bending themselves with laughter. The story managed to get back to my Mum who said to the staff, "Kate must have been angry to come out with something like that".

My brother is a policeman, and the stories he tells about what some people say to him would curl your hair. He is just doing his job, but I don't think they worry about this — they just give him a mouthful of abuse.

In a milder form of swearing as an aggressive act, swearing can be used to keep people at a distance. This can be important for people with disabilities if others patronise them and treat them as children, or strangers get inappropriately 'matey' with them.

Kate comments :

Sometimes people stand too near me and get too familiar. I think to myself, if they don't stop that I am going to put my head pointer in their

eye. But instead what I do is come up with a choice word or two that makes them keep their distance.

Swearing is also used, not to have a direct effect on another person's behaviour, but to emphasise a point by marking it with strong language.

Kate comments :

I have a cat called Lizzie and I am sure she understands the swear words! For instance, there was one night she was away too long and I decided to go out and look for her in the freezing cold. Eventually she came home and what she got from me ! The words "bugger lugs" were used and these words have been used again on several occasions since then.

It is commonly observed that the overuse of swear words can reduce their potency. Using them to mark out parts of what is said as being particularly important does not work if almost everything is so marked. In Brophy and Partridge's account of soldiers' slang in the trenches in the 1914-1918 war, they make an interesting point that can follow from this :

... if a sergeant said, "Get your ____ ing rifles!", it was understood as a matter of routine. But if he said, "Get your rifles!", there was an immediate implication of urgency and danger (Brophy and Partridge, 1930, cited by Montague, 1967, p.310).

There are settings in which it is expected that speakers will swear constantly — usually all male gatherings, but not necessarily. Here the swearing acts as builder of group solidarity, as if to say, "This is the way that we speak, not like those posh people out there."

Kate comments :

Some places I attend, people come out with bad language and every second word is either A, B or C. I don't feel their education is very high if they can't express how they are feeling without continually swearing.

Augmented communicators and swearing

Given the effort involved in producing even small amounts of augmented communication, a form of language which carries particular vividness and power should be of great interest. And given the comparative lack of control over others which people with disabilities can have, a means of achieving more control over other people using language should be seen as important. Interestingly, the opposite seems to be the case. It has been our observation that the use of swearing by AAC users is not as common as its use by natural speakers. This may be for several reasons. To swear, the AAC user will need to have the appropriate words stored on the system they use. There can be problems with this. Teachers and parents may be reluctant to help a young person enter the words into their system. The way most children learn about swear words is by hearing adults or other children use them. The words then automatically become 'theirs' and if they wish they can employ them later. The AAC-using child has a much more cumbersome procedure to go through, and with the embarrassment most of us feel about swear words, this process can be put off the track at several points. (Note that this embarrassment is itself testimony to the power of these words over all of us. Again, it is similar to handling explosive or dangerous substances.)

Another important factor in the censorship which can be imposed or self-imposed on AAC users is the tendency of able-bodied people to imagine that people with disabilities either are not mature as adults or if they are, they have some sort of special virtue compared to people without disabilities. This strange phenomenon has been noted by many writers on the subject. Sometimes writers on disability will refer to it as the 'tragic but brave' label. Perhaps the most scathing general observation on this phenomenon was made by Bertrand Russell, who noticed that we can tend to project a superior virtue onto oppressed people generally, and that this ironically is one way we can justify continuing to oppress them (Russell, 1950).

It also happens that people with disabilities can feel a pressure to be more pleasant and upbeat at all times than other people. The reasons for this could form the subject of another article, but it is commonly experienced. A line from one of AAC user, Alan McGregor's songs puts it very strongly, "I'm getting sick and tired of putting on this show, trying to look happy for you." (McGregor, 1991).

Kate comments :

When I was small and sitting outside in my chair I swore at somebody across the road because he had said something, so I said to him to 'bugger off'. Everybody thought it was funny because they didn't think I could say something like that. There was another time when my sister swore and came out with an 'F' word, and everybody was shocked. When people like myself come out with a swear word, I feel it isn't acceptable to able bodied people because, I think, they think people like me don't know how to swear.

As has been pointed out, AAC users have particular problems when it comes to swearing because often they are dependent on care-givers or therapists to enter words into their system for them. Parents of disabled children have particular problems when it comes to giving their child

opportunities to take risks. This is very difficult for any parent to do. The fact is, with their able-bodied children (and teenagers), they can't stop them. This lack of total parental control has the effect of ensuring that young people get the opportunities they need to experiment, take risks, and hopefully not suffer too badly with the consequences. (But note that there is no guarantee about this).

So a key part of growing up can be denied to young people with disabilities because their parents or caregivers must actually facilitate them being at risk in order for it to happen. One of the vivid aspects of Christy Brown's upbringing, described in his book *Down All the Days* (Brown, 1970), was the role his brothers and their pals had in making sure he took part in all sorts of escapades which would have horrified his mother. This suggests a way to assist AAC users to use swear words when they feel it is appropriate — training siblings and peers to enter words in the AAC user's system. This would parallel the way that speaking children acquire these powerful words.

Another aspect of swearing with AAC that is unusual is that AAC is more like written than spoken communication, certainly in the way it is produced. Normally, the words to be spoken are displayed before they are spoken. Having a swear word written out is very different from it just being a sound. It can cause unwanted amusement if an onlooker sees it. Particularly if the words are on a selection display and may not be in use at the time, the fact that they are on view can cause embarrassment or discomfort. Here perhaps is a challenge for designers of AAC systems — Computer-Assisted Swearing.

It must be possible to devise a method of allowing users to select and output swear words while avoiding having them displayed overtly. Using a graphic symbol for each word may be the way to do it.

A related technical and design challenge is to have swear words ready for very quick output (otherwise the effect is lost) without having them inappropriately prominent on a display.

As well as this suggestion, there may be innovative and clever ways that AAC systems can be designed or used in order to facilitate swearing. We think this is an issue of basic communication rights, and not something for which AAC users should have to negotiate. A possible reaction to our arguments might be, 'Children do not know how to use these words appropriately and will undoubtedly use them inappropriately, certainly at first.' Our response would be to say this is absolutely correct. And the way that speaking children learn what is unacceptable behaviour is to try it out and be told off for it. Children (and for that matter, adults) using AAC need to learn in the same way.

Conclusion

Swearing is a powerful and widespread form of language. Its use can give the speaker increased control over others and a more powerful way of speaking. The fact that it can be misused applies to speaking children and adults just as it does to AAC users. As a lively and effective form of communication it needs to be made available more easily to AAC users. This is a matter of clever system design, and also one of changing attitudes among those who have a degree of control over the AAC user's communication. As an issue for all those involved in AAC this one is damned important.

Acknowledgements

Thanks to Annalu Waller and Joan Murphy for their comments on drafts of this article.

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Have you moved?

Please send us your new address.

POET'S CORNER

JAMES STUART

Jim Stuart

It doesn't matter
How much technology I have,
It takes communication to make it work!

* * * * * * *

Making It

by James Stuart

People said that I'd never make it
Make it out here on my own
They said that I'd be lonely
Some even said it would be too tough.

But here I sit day after day
Night after night, week after week
Month after long month
And I'm still making it go.

Sure there have been lonely times
Sure there have been times when I've
Felt maybe all those people really knew
What they were talking about.

But then I think about it for a second
And that would mean that I didn't make it
Which only makes me look at things
Just a little bit closer and take a little time.

Just a little more time, a little more care
Tell myself that this is what I wanted
Wanted right from the very beginning
I wanted a chance to prove that I could make it.

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I look forward to including poems written by our readers in the Poet's Corner. Our theme next issue is "The Caregiver". Do send me your thoughts on this topic to:

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Kitchener, On., Canada, N2M5 5G6
email: jstuart@golden.net

REFLECTIONS

NOLA MILLIN

Nola Millin

Welcome to a brand new section of **Communicating Together** called *Reflections*. The intent of this section is to provide users of augmentative communication (AAC) and parents of AAC users a means to present their perspectives on issues that effect us. The people who have been reading this magazine for a while will hopefully know that I'm an AAC user (with a *big* mouth!). It seemed fitting for me to take charge of this section because I feel AAC users and/or parents have a lot of wisdom to offer since we live with AAC.

As I thought about this section, I realized that often users and parents have things to share but might be scared to take on the responsibility of writing entire articles. I'm not expecting people to write entire articles for me — *unless of course someone wants to* — but I'm hoping to get feedback from people. I will take the feedback and incorporate it into the articles I write. I would like to get some opposing views from consumers and to determine what the hot issues are. Although I'm hoping to stay within the themes of each **Communicating Together**, I realize that I might get autobiographical material from people. I will certainly be willing to put such material in this section. In other words, if you are an AAC user and/or a parent (or family member) of someone who uses AAC, this is an opportunity to help me make this section a success.

People can reach me at: 110-3185 Forest Glade Dr., Windsor, Ontario, Canada, N8R 1W7, or by fax at 519-735-4443, or by e-mail at: Nolamillin@aol.com. Hope to hear from you.

Now, let's have a look at our theme — *Communication NOT Technology is What Counts.*

I strongly feel that the act of communicating is far more important than using the best technology. I have a word board that is held together with duct tape to prove my point. I use my word board for a lot of my communications. Also, people who are around me a lot can understand a good portion of my verbal speech. In certain situations I would rather use my speech and word board then my voice output communication device. Yes, there is a time and place for technology in my life. Those of you who have been reading my articles for a while know how technology has helped me. I now have a Motivational Speaking Business and I rely on my AAC device to deliver my presentations. I do some desktop publishing and multimedia editing between speaking engagements so I certainly rely on technology. I don't want to think of my life without e-mail these days. My computer was in the shop for 24 hours the other week. When I got it back and checked my e-mail I had something like 50 messages. So, obviously I'm not against technology.

What I am against is the mentality that technology is the answer to everyone's problems, especially AAC users. I'm also opposed to the concept that "better is always best." A few months ago I had someone over at my place who knew of a child who had a speech impairment. Apparently, the mother wanted to get the child an AAC device but, for some reason, the speech-language pathologist was opposed to it. This person was asking where I got my device and the steps needed to get one. I think I managed to avoid answering the question directly. My fear was that while this parent probably wanted the best for her child, she might be putting false hope in technology. I wondered whether or not this child was really ready for technology or whether a low-tech. method of communicating might work better. I'll never know the answer. I wondered, too, if the parent was caught up in the "better is best" mentality. She might have felt technology is better then a word board or picture board. I often joke at how my word board never breaks down. I can use it in the rain and sand, and I don't need to charge it!

In order to fulfil my intentions of this new section, I joined an AAC Users Group that's on-line. When I posed the question of what really matters — technology or communi-

cation, I received a lot of responses that seem to have a common theme and support my views. Here is what members of this group said:

Jon Feucht, from the U.S.A., had tried various devices but couldn't find one that met his needs. People persuaded him to keep trying devices since Jon wanted to move out on his own. Eventually he tried a Liberator and caught onto it right away, which I can relate to. Within a week after getting his Liberator, Jon gave a speech at a conference with it. Jon soon began using his Liberator to make phone calls and was able to get a hold of people he hadn't talked to in years. Jon says, "The Liberator has boosted my confidence in my communication. I know in the future I'll always have the Liberator. It is a phenomenal device. I have complete confidence in it."

Mary Ann, from the U.S. told me: "I believe that people having moderate to severe speech impediments should have communication aids. However, I too think most of us don't need the most sophisticated communication aids in order to communicate efficiently and easily. The reason I feel that persons who have moderate to severe speech impediments should have communication aids is that they can help to make many of us more relaxed. This can allow us to use our own speech more than we would if we didn't have communication aids." Mary Ann adds that when she's with people who know her, she uses her Vois 160 only occasionally, but she always has it on her power wheelchair during the day. She wishes she could have it after her attendant is gone at night. She puts herself to bed but needs someone to plug in her device. This means she has to be without a communication device for a few hours. Mary Ann concludes with, "Since technology is all around us, I think we should take advantage of it, but we shouldn't let it control us."

Fiona from Sydney, Australia writes: Like you I can use my voice with my family but I use a LightWriter in public. I agree that it's communication not technology that matters. Whilst technology is important & useful, I tend to think sometimes it is used as a "quick fix." I remember when I was about eleven, my speech pathologist said here is a Canon Communicator and then more or less said, "No more speech therapy". This really annoyed me because it was as though she was giving up on my speech. It is important to realise that for people like you and me who do have some speech, technology is not to replace our speech, it is there to supplement our speech.

Graham Clarke from Cape Town South Africa expresses similar feelings. He says that people tend to be "blind" at first, especially when the disability happens after birth. Graham feels people think that the most expensive equipment, be it communication devices or wheelchairs, will help lessen the disability they must all face together. Family members generally focus on the end result hoped for from a disability device and never stop to think how much effort and training are required for the person to use the device efficiently. This relates especially to communication. He feels that simple communication in the beginning helps those around the person establish what the person's abilities are, how long they can concentrate, etc.

Barry Romich, a technology specialist from the U.S.A. shares similar thoughts. Barry says, "From my perspective your question is a no-brainer. We've been warning people for many years not to be sucked into the technology trap. While technology can be a means to communication, technology is of far less significance in that quest than language. In some ways, technology advances have been detrimental to the field of AAC. When people fail to understand the issues relating to language representation methods used in AAC, they can be misled by technology. And without a strong language foundation no technology can result in effective communication."

I only received one response from a parent — June, from Kentucky, U.S.A. who has a 19-year-old son. She says, "Communication has always been a huge frustrating challenge for him. We have struggled to best meet his needs and have not been particularly successful. We have tried high tech, low tech and no tech. He has been trained to use a variety of devices with some success but none that greatly enhance his communication skills. We have found that the more means that we can give him to spontaneously communicate (because he too has a lot to say) the less frustrated he is. We use low tech in some situations and high tech in areas where we can better predict his communication needs."

As I look over all of these responses, it's pretty easy to see that all of the respondents feel that communication is much more important than having the most sophisticated devices. We all seem to agree that when technology is used, it's more important to get a device that works for the individual than it is to have the 'latest & greatest' device available. When a person finds a communication device, or devices, that work effectively, that in

essence for them is the greatest device out there. I know I think my laptop computer hooked to a multi-voice is one of the best devices for me. Then again, I wouldn't give up my word board. I don't want to speculate on which device is better for me because they both enhance my ability to communicate.

In closing, I want to mention Speech-To-Speech. Personally, I haven't used this service but apparently it's available in various states and is being tested in a few other countries. Speech-to-Speech is a new, free telephone assistance service 24 hours a day. It provides human voices for people with difficulty being understood by the public on the telephone. It is expected that all states will provide Speech-to-Speech in two years. If you have a speech disability, you can dial toll free to reach a patient, trained operator who is familiar with many speech patterns and has acute hearing. This operator makes telephone calls for you and repeats your words exactly. Speech-to-Speech is also useful if you use a speech synthesizer. Speech-to-Speech is the only way for many people to telephone others not accustomed to their speech. Many Speech-to-Speech users have Parkinson's disease, cerebral palsy, multiple sclerosis, or muscular dystrophy. Other users include people who stutter or have had a laryngectomy or ALS. You can try out Speech-to-Speech, report problems or get more information by calling 800-854-7784 and asking for Dr. Bob Segalman. Bob uses Speech-to-Speech himself and likes it.

I believe, when all is said and done, people all feel it is communication, not technology that matters! Technology is what *helps* some of us to communicate effectively.

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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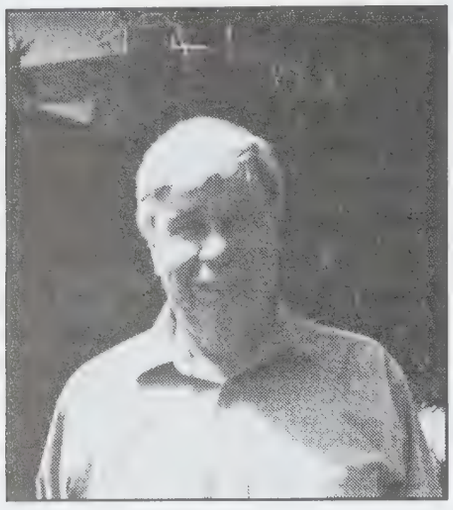
Communicating on the Electronic Highway

PETER LINDSAY



Peter Lindsay

This is my first article as the person responsible for the 'Using Technology' section of ***Communicating Together.*** *I want to personally thank Robert Haaf our former Associate Editor for 'Using Technology'. Robert has a new job as Professor of Audio-Visual and Multi Media at Fanshawe College, London, Ontario, and reluctantly asked to be relieved of his role as an associate editor for* ***Communicating Together*** *until he got his new responsibilities under control. We hope he will return as soon as possible. On the condition that he promise to return as soon as his life settled down a bit, we reluctantly accepted his resignation. Thus, at our annual meeting, I agreed to be responsible for this column as well as for our* ***ComTog Online*** *website.*

When thinking about the content for the *Using Technology* section for the next year, I decided that in general, it was important that the articles in this section deal as clearly as possible with the p*ractical* and *functional applications* of technology as well as any theoretical issues that may underlie those applications. I also felt that the writing should be as free from the usual 'computerese' as possible. Those of us who work with computers on a daily basis are sometimes not even aware that the language we speak is a foreign tongue for many who are not so familiar with computers. To provide an external check on this, prior to publication of this article, I submitted it to the parent of an AAC user who is slightly techno-phobic about computers but who is eager to learn. Since she is just undertaking now to learn to use a computer, she agreed to check both on the practical value of the article to her as a parent as well as to establish its jargon quotient.

In addition to focusing on practical applications and providing jargon-free descriptions and explanations of technology, I also want to make this section as relevant and useful as possible to the various classes of readers of this magazine — to parents and caregivers, to clinicians and to the AAC users themselves. To help with this, I will be asking you for your input both informally as well as with more formal surveys from time to time. I plan to set up an electronic dialogue on our Website to facilitate reader feedback and ongoing commentary.

In terms of the specific content, I plan to deal with the implications of technology for the theme of each issue. In addition, over the course of the year I would like to deal systematically with what I believe to be the single most important new technological development for AAC users around the world — the rapid emergence of the Internet. In terms of new opportunities for communication as well as the potential for long term dramatic improvements in their quality of life, the Internet in my opinion will have a far more significant impact than the computer itself. I realize that at present, the Internet is not simple to use, particularly for those with limited literacy skills or who rely exclusively on alternative graphics systems to communicate. But we must understand what its potential capabilities are as well as what, specifically, we can use right now. We must then demand from our manufacturers and our clinicians that this new communications medium be made fully accessible to the AAC community. Otherwise, this revolutionary social development will result in the AAC user falling even farther behind in his or her ability to keep pace with the rest of the world.

Well that is enough about the general plans for this section for the upcoming year. Let us turn now to the theme of this issue

Communication NOT Technology is What Counts!

When thinking about what a section of *Using Technology* might contribute to the theme for this issue, I at first felt slightly on the defensive. The theme certainly seems to have a negative connotation towards technology. I agree fundamentally with the underlying premise that technology can in fact get in the way of communication and inhibit it rather than promote it. On the other hand, I am still convinced that we must somehow come to grips with technology because it has such a very fundamental contribution to make to the quality of life of AAC users. After some thought, the theme seemed to fit in very well with the other objective of the *Using Technology* section — the desire to discuss the basic *communication* functions of the Internet.

A New Worldwide Accessible Library

The new possibilities introduced by the Internet can be considered in three broad new areas. Each of these will be described and discussed in future issues of **Communicating Together**. The first of these new functions is its *library* function. If it is not already, the Internet is rapidly becoming the largest repository of information in the world. One can find information on the Internet on almost any topic one has an interest in whether it is previews of the latest movies, reviews of the current best selling books or the symptoms, diagnosis, and prescriptions for common as well as esoteric diseases. Since the widespread use of the Internet to find information, doctors are increasingly complaining that their patients come to them knowing more about the latest research on their ailments then the doctors themselves.

Unlike standard libraries however, anyone can make a contribution to this new worldwide library. This means that we, as a world community, have the joint responsibility for building the library. It also means however that there is no control over the quality, accuracy or completeness of the information one finds. Furthermore, its sheer size combined with the relative limitations of the current "search engines" that are used to find information on the Internet, means that one must have a great deal of patience and be willing to look through a large amount of irrelevant material when looking for information on the Internet.

On the other hand, the information in the Internet library is not restricted to text. It can store pictures, and video and sound bites as well as any kind of formatted text. In a future issue of **Communicating Together** I will discuss this library function of the Internet.

Distributing Information

A second major function of the internet is to store and distribute files whether they be computer programs, tax returns or the latest hit record. Most companies that create computer products can, at the click of your mouse, send you (i.e. "down-load") products right to your local computer. One of the most popular of the Internet sites is operated by a giant bookstore with no shelves —*amazon.com*. At this site, you can read the reviews of almost any book that interests you and order it if you want. When ordered, it usually comes within twenty-four hours. *Amazon.com* also has a giant record library where you can hear samples of the tracks of any record as well as read reviews, submit your own reviews, or have the record or CD itself sent to you.

The next step for print material like books will come when the book seller is able to send you the complete book as a computer file that you can then read on the screen or print it so that you can read it "off-line". When this happens it will revolutionize the publishing business. Printing, shipping and warehousing massive numbers of books in the hope that they will be sold will become a completely obsolete approach to publishing. In fact, the final step — the direct shipment of the product — has already arrived for the record industry. This is largely because of the development of a new encoding format called MP3 for transferring audio information between computers. This format is so fast and efficient that it is feasible to send complete records or CDs right to your computer on command. Moreover, what the customer receives is a *digital* version of the material, which is a "master quality" recording of the requested music. The music can in turn be played directly on his or her computer, or, just as for books, can be "burned" into a CD using the person's personal CD burner to make a regular audio CD. This can subsequently be played on a CD player just like any other CD.

The net result of all this is that it is now a relatively trivial matter for the average person to become record producers and distributors. In their own basements, people can copy tapes, records or CDs onto their computers, convert them into a digital format, then make them available to anyone in the world though their own websites. In fact, this technology has advanced so far that now the large commercial record companies are becoming very concerned about the "pirate" sites that are distributing music directly though websites without the copyright of the original records. They are scrambling to set up their own competing Internet sites to make the world of music immediately accessible over the Internet.

Communicating

The third and final new area of functionality that has emerged with the development of the Internet is probably the most significant one for AAC users. This is the widespread use of a new medium for *worldwide interpersonal communication*. This communication medium supports relatively simple things such as sending a text message to a friend or having a group discussion among a large number of people. It currently will also support much more complicated situations such as a meeting among a group of people who are spread all around the world and who need full audio and visual contact to conduct their meeting. All of these activities are currently supported by the Internet. The first, simplest and most widely used of these interpersonal communication tools is electronic mail or *e-mail*. This is the one we will begin to consider in more detail in the present issue.

Interpersonal communication

The objective here is to be able to compose a message one wants to communicate, then send that message to someone one wants to communicate with. To make it useful for individuals who have profound physical disabilities, there is an additional requirement, namely that, if possible, all of this must be able to be done on an accessible computer without having to leave one's room or to ask anyone for help. Otherwise, one could compose a message on a computer, print it out, then have someone address, stamp and mail it. With an e-mail program, one can do the addressing, stamping and mailing right in the computer. In fact that is precisely what an e-mail program is designed to do. Let's look a little more closely at what these e-mail programs do, and then review what you might want to use e-mail for.

There are four basic steps in sending an e-mail message:

1) compose the message you want to send
2) attach the recipient's e-mail address to the message
3) place the message in an "outbox" with the other messages that are waiting to be sent
4) tell the computer to send the e-mail messages you have created in your outbox and transfer any e-mail messages waiting for you to your inbox.

Ordinarily for most e-mail programs, at the time it is sending the messages you have composed it will also transfer any new messages that have been sent to you from your ISP's computer into an "inbox" in your own computer that has been set up for that purpose. This procedure is called "downloading".

Another feature of the better e-mail programs that are most appropriate for AAC users is that all of the composing and reading of the e-mail messages are done when the computer is not actually connected to the Internet, — when the computer is "*offline*". This makes the program an "offline" reader. This is a very important feature if the message-composing and message-reading is slow, as it tends to be for persons using AAC.

1. *Composing E-mail Messages*

The first step in creating an e-mail message is composing what you want to say. Most e-mail programs will let you use whatever word-processing program you prefer to compose the messages. Most also have their own built-in word-processors. It may not have as many features as the dedicated wordprocessor you typically use but they are quite adequate for the task. If the message is being composed on a separate wordprocessor, once it is composed, it has to be loaded into the message space of the e-mail program usually using a cut and paste operation. When you use the editor provided by the e-mail program, you enter the text directly into the message space.

2. *Addressing the Message*

The next step in preparing an e-mail message is to add the e-mail address of the person you want to send the message to in the slot provided by the program. Some programs require you to enter the e-mail address before you enter the message itself. Most programs allow you to send a message to many people at the same time simply by adding their e-mail addresses to the list of addresses of where the message is being sent. The e-mail program will also provide a place where you can indicate where to send *copies* of the message.

All e-mail addresses include two basic parts separated by an "@" sign. The first part is the *Username*. The second part is the *address of the Internet Service Provider* (ISP) whom you have contracted to send and receive your e-mail.

The Username is something you select in collaboration with your ISP when you first sign up for the service. Although many ISPs allow pseudonyms, the Username is most often some combination of the parts of your real name. My ISP for example usually uses the initial of your first name followed by your full last name. For example, my name is Peter Lindsay. Thus my *Username* is "*plindsay*". I am using the University of Toronto as my ISP. Its Internet address is "oise.utoronto.ca". Thus my full e-mail address is:

plindsay@oise.utoronto.ca

Note that there are no spaces and no capitals in the username. For many ISPs, (mine included) capital and small letters are treated as different and spaces are not allowed in Usernames. Thus it is important to enter the e-mail address exactly as specified. Inserting capitals or spaces will cause errors.

Making address mistakes: There are two places where you could make a mistake in the e-mail addresses. If you make a mistake in the *ISP address portion* of the address, your e-mail program will find it right away. The first thing your ISP does when receiving a request from you to send an e-mail message is to look up the ISP address portion of the message. If it does not find it, it will tell you that there is no such ISP. If you make a mistake in the *Username portion* of the address on the other hand, it will take longer to notify you. It has to first send the message to the ISP you specify. At that point the receiving ISP will try to look up the username you have given. If it cannot find it, it will send a message back to you saying that the Username you have specified is not registered as a user for that ISP.

Nicknames: E-mail addresses can get long and complicated. To simplify this, most e-mail programs will allow you to use *Nicknames*. The association between the nickname and the real e-mail address is usually contained in an

"Address book". I usually use the person's first name, and perhaps the first letter of the last name if needed to distinguish it from others, as the nickname. Thus if I wanted to send something to Shirley McNaughton at "freespace.net", I would enter the name "Shirley" in the nickname field and "smcnaughton@freespace.net" in the e-mail address field. When I then enter the name "Shirley" in the address field of the e-mail message, the program will substitute the full e-mail address of

smcnaughton@freespace.net.

3. *Place the message in the "Outbox":* This is usually done as part of the composing and addressing of the message. Sometimes you have access to the *Outbox* directly and can see the messages that are currently waiting to be sent. You can also take them out of the Outbox or edit them again before sending them if you wish.

4. *Sending the messages:* Most e-mail programs have an explicit command for actually sending the messages that are waiting in the Outbox. As noted above, ordinarily messages are not sent until you give explicit instructions to the program to do so.

5. *The subject of the message*: In addition to the basics of composing e-mail messages, most programs also provide a place to indicate the *theme* or *topic* for the message. Here you enter the overall topic of the message you are sending (e.g. "Meeting on technology").

6. *The Reply option*: This option makes it easy for you to respond to a message you have just read. When you select the *Reply* command, the program will automatically insert the correct address, copy the *Topic* field from the message you just read into the topic field of your reply and then ask you if you want to include a copy of the message in your reply.

7. *Attachments:* A final common feature of most e-mail programs is the ability to send *attachments* in addition to text messages. The attachment feature is used when you want to send a complete file via e-mail that you may have prepared for other purposes. Attachments could be tax spread sheets, baby pictures or whatever file you want. Unlike the text files that are sent in the message space of an e-mail message, attachments are appended to the e-mail message and the format of the attached file is preserved exactly. The file itself must be read by the same kind of program that produced it. Thus if the file was originally prepared using a spread sheet program, you will need to use a spread sheet to read it after you have downloaded it onto your computer.

Different e-mail programs handle attachments somewhat differently. Some require you to first upload the file you want to attach onto the hard disk of your ISP. Once there, you can attach it using the "Attachment" command provided in the e-mail program. Similarly when receiving an attachment, before you can read it you must first move the file that has been attached to the hard disk of the ISP then use another program to download it to your computer. Some of the newer e-mail programs have now automated the way attachments are dealt with so they are much easier to handle.

The above then describes the basic capabilities of e-mail programs and the basic sequence of operations for composing and sending e-mail messages. All programs provide for these basic functions in one way or another. The exact commands may differ somewhat but the functions are the same for all of them.

As e-mail programs become increasingly popular, new features are being added. Many programs will now allow you to embed pictures, videos and even spoken text right into the e-mail message you are composing. Most will allow you to set up mailing groups in your address book so you can easily send the same message to a group of people. A number of programs will allow you to use the same language you use for setting up websites and will automatically process it appropriately when it occurs.

What would I use e-mail for?

Now that you know what the functions of e-mail are, the next question is what might you use e-mail for. The simplest answer is that, in principle, you could use e-mail in any situation where you would otherwise write a letter or make a phone call. To use e-mail of course, the intended recipient must have an e-mail address and access to a computer.

Increasingly most people or organizations you might want to contact have e-mail addresses. This includes health services such as doctors, speech therapists, hospitals and other health professionals, as well as professional organizations involved in AAC and AAC manufacturers and distributors. Every level of government and politician can now be accessed through e-mail. Even other AAC users are gradually beginning to experiment with the potential of this new electronic highway and hence make themselves accessible through e-mail. More and more, the people I meet routinely have their e-mail addresses on their business cards. In fact, the significant advantages for the user of AAC in using e-mail, means that it is quite appropriate to demand that those who are working with them should be accessible via e-mail.

In the next issue, I will discuss the advantages of e-mail over regular mail and what you need in order to begin e-mailing. For the addresses for some relevant Internet Web sites see page 23. §

CLINICALLY SPEAKING

TRACY SHEPHERD

Tracy Shepherd

Hello there ***Communicating Together*** *readers. I am back! After a short maternity leave filled with twins, laundry, and diapers, I am sitting at the keyboard to try to sort out my thoughts (which may be a bit fuzzier than usual).*

This new section called 'Clinically Speaking' was born at the last Associate Editors' meeting. We see it as a forum to discuss clinical information and ideas. Since many clinicians read the magazine, it seems this section should approach the theme from the clinician's angle. What issues are we facing? How are the issues being resolved?

Input from clinicians working with adults and those working with children would be a welcome addition since the issues each is tackling are often very different. We would also like to compare and contrast what is happening in other countries related to the theme. The comments I get regarding the magazine are typically from clinicians who have read an issue and have enjoyed the controversy it stirred up. Unfortunately, I think we are all searching for definitive answers to problems and often there aren't any. It certainly is nice to bounce around problems and successes to share with one another what is working and what is not.

Now onto the theme of this issue ***— Communication, NOT Technology is What Counts.***

Although I am sure we would all *say* that it is really communication that matters, in reality, are we able to put that into practice? I see so many of us (clinicians) getting so caught up in the technology and what it can do (when it is working), that we sometimes lose sight of the other issues tied to the use of technology itself. I don't think we necessarily mean to do it, but we do. So this is where I start making excuses. There are only so many hours in the day for us too. We have to keep up to date on so many different products and the technology changes so fast. (I am afraid to go back to work and see what I have missed and what I need to get caught up on.) If we don't appear to know a lot about every product, parents looking at us as the experts seem to lose respect. Since we are the "computer people", that is what consumers are often looking for from us — technical stuff. We need to have the respect of our clients which means we need to feel like we know it all. Well, at least some of the technology and what it has to offer. Technology is wonderful and opens so many doors but we have to be careful not to let it take over our clinical lives. Low tech is certainly much more reliable. Even in our everyday lives computers are supposed to make it easier. I see computers causing more ulcers on a day-to-day basis than I think they are worth. In an office setting networks go down, printers jam up and cables break. We all need to have a low tech back up. What about the person who spends 30 hours preparing a Power Point presentation who gets to the presentation and the light bulb to the overhead projection unit has blown out? Then what?

I know I have written on this topic before and I could get long winded. This time, I am referring to the Plenary Session at the Isaac conference, in Dublin, Ireland, 1998, entitled "Microchip or Micro culture: Does technology help or hinder communication?". It was an excellent debate that presented each side of the issue. There was a bit of time for comments from the audience and it was interesting to hear consumers saying how much they depend on technology and how their lives would not be the same without it.

In the debate, Dr. Jeffrey Kallen of the School of Clinical Speech and Language Studies, Trinity College, Dublin, discussed how technology is neither good nor bad for communication. Communication he argued is much more complex than what technology can or cannot do for us since communication itself is so complex. He reminded us that technology will never be a substitute for thinking and feeling and that as advanced as the technology gets it

will never operate itself. He outlined the problem that technology distances people and removes the human element as more technology is applied. He remarked that the humble microchip becomes the symbol for ultimate human freedom. He also illustrated the all important truth about technology in the AAC field — inequality of availability — creating the "haves" and the "havenots". His presentation was a good discussion of technology and the dangers surrounding its use.

On the technology bandwagon was Janet Larcher from the UK who painted a portrait of a young boy whose life is virtually dependent on technology in all aspects from communication to driving to feeding. To be noted from her excellent illustration of the need for technology was that for this fellow money was no problem so he was able to "have" the best available technological solutions. This discussion certainly made one realize that technology is wonderful and can and does make substantial differences in many lives, when it works, is accessible financially and is supported by the individual's environment!

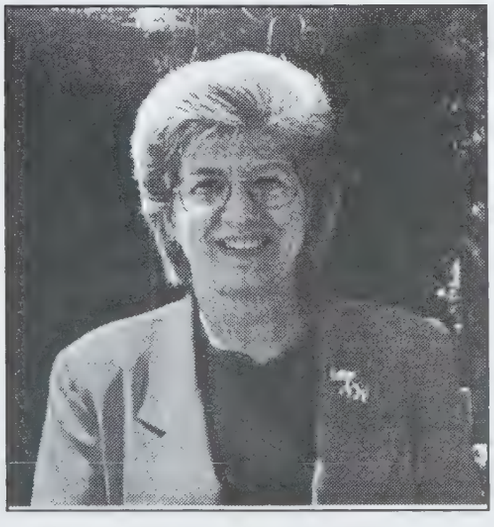
Summing up the discussion on both sides of the debate, Dr. Annalu Waller, Department of Applied Computing, University of Dundee made the all important statement that technology provides us with a unique *tool*, which she pointed out should be harnessed when it can add to an individual's communicative repertoire. She stated "Technology can help immensely. But it can also hinder if it is used for its own sake". This is so true!

It comes down to first identifying the needs of the individual and shaping the technology around these needs. It is of prime importance to have the technology meet the needs and not allow the needs to be created by the technology. I am reminded of a communication device that I was recently told can now hold 8000 hours of recorded speech (I exaggerate). When I asked "why?" The answer was "Because we could". I don't get it!

§

WHAT NOW?

SUZANNE CLANCY



Suzanne Clancy

Welcome to the *What Now*? section of **Communicating Together**. This is a new venture for me, one that I hope will generate interest, feedback, insight, and creative solutions to many of the needs and expectations of AAC users. The title for this section grew out of my years in the post secondary field teaching life skills and employment readiness to adults with special needs. Untold numbers of AAC users have asked me "What can I do now that I have completed high school?" Such questions (and others) are the ones that I hope we can discuss in this section.

I begin by commenting on the theme for this issue, *Communication NOT Technology is What Counts*. I couldn't agree more for the AAC user. I remember vividly my introduction to the world of nonverbal communication. Paul Marshall (*Paul's Pulpit*) applied to my college program. I agreed to work with Paul and proceeded to research the history and use of Blissymbolics. Totally intimidated, I turned to Paul to train me in the use of augmented and alternative communication. He did an admirable job and together we added signs and symbols to his board for use in group discussions, goal setting, career research, and for work. Our biggest challenge was finding the time to add a column or two to his board.

After a structured remedial literacy program, Paul "graduated" to traditional orthography and began using an alphabet board. This form of communication greatly enhanced the speed and efficiency of communication and was much easier for his

classmates to understand. And it had the side benefit of being a spelling lesson. More than one fellow student learned to decipher and spell new words while "talking" to Paul. As technology advanced, Paul acquired his first voice output device, then his laptop, along with all the attendant hardware, software, cables, wires, batteries and problems. In spite of all this fancy technology, when we wanted to have a serious discussion, or private chat, we returned to the tried and true alphabet board. In all the years, it has never failed us, broken down, or lost "data". As Paul mentions in his article, while he now uses multiple forms of communication , his alphabet board is still on stand-by. Paul remains my barometer and reference point in the use of augmentative and alternative communication.

In recent years I have attempted to accommodate various other AAC users in my program only to discover that technology has been more of a hindrance than a help. First, I often find that the AAC user comes with a highly preprogrammed vocabulary which, while relevant in other settings, is limited in intake interviews and eventually in employment as well. To further complicate matters, the time required to program additional words or phrases, and train the user, is generally excessive and can range from weeks to months or more. One potential student has been waiting three years for an adequate communication device. Government cutbacks have been cited as one of the more important causes for the delay.

Second, often students arrive with the latest equipment, trained and ready to go, only to have the device break down, or be incompatible with classroom transportation. Too often the high tech device takes on a personality of its own among classmates, and consigns the user to the secondary position of object communication.

Third, many AAC technologies take an inordinate amount of time and effort to master and use efficiently, time that is often at a premium in the home, the classroom, the workplace, or just between friends. This then becomes a problem of perception, value, personal worth, and common courtesy. AAC users have every right to expect that people will take the time to listen to what they have to say, but too often the listener becomes frustrated, bored, disinterested, or distracted when a user takes several minutes to reply. What is really needed is a user and listener friendly, inexpensive, durable, flexible, and adaptable device that does not require advanced degrees on the part of the user to use.

I do, of course appreciate computer technology and its use as communication tool. Word processing and e-mail are invaluable aids to communication. As Paul and Nola so aptly point out, their life and work opportunities would be greatly hindered if not for access to computer technology. But the underlying premise should always be communication first, not technology. Over the years many of my most meaningful conversations with AAC users have occurred without the use of high technology. The nod of a head, a smile, a shrug, a knowing look — simple but eloquent gestures that 'speak volumes'.

I am especially interested in hearing from AAC users who have pursued education, training, or employment. What were the barriers? How were they overcome? And how might those working in the field facilitate full participation for AAC users in all that life has to offer? Your experience can help us all do better. I welcome any suggestions or comments on articles in this section, as well as submissions.

I can be reached at:
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§

Re ComTog OnLine

You will notice that the banner on our cover contains the new address for our **ComTog OnLine** website — **comtog.net**. We had to change our address because we needed to change our Internet Service Provider. A notice to all **ComTog OnLine** subscribers informing them of the pending change was included in the last issue of **Communicating Together**. We apologize for the disruption of access while arrangements were being made. For those who wish to browse and explore a sample of the online issue, we invite you to check out our new website.

AS COMMUNICATION CHANGES

Communication?

ALDA STEPRANS

Alda Steprans

This section of **Communicating Together** is about people whose ability to communicate has been altered because of illness. They have lost the ability to communicate verbally, usually after some disease that involves the nervous system. My first exposure to **Communicating Together** made me aware that many of the people I worked with were having many of the same difficulties as people who were born with the inability to communicate. Many of the writers of **Communicating Together** provided me with great insight and I wanted to share it with my friends — the caregivers and residents of the hospital I lived in. I also wanted to make others aware that the residents of chronic care hospitals, who have lost or are continuing to lose many of their abilities, are still very capable and able to continue learning.

I am sorry that we won't have an article from Steven Hanlon in this issue of **Communicating Together**. Steven was unfortunate and caught one of those incredible superbugs requiring him to stay in isolation for a bit. I know this was a difficult time for him because he so loves to "get out and go" every day. Steven had to be careful not to breathe on other residents of the chronic care hospital he lives in. Many of them are in fragile health and could die from such an infection. Luckily, Steven was otherwise not badly affected by the bug. He is now out of isolation and as happy as ever. I hope to help him in the writing for the next issue soon. Steven does not use any technological device to communicate — he does use a letterboard, to show the first letter of a word he is saying and a lot of determination and persistence. I often wonder about what words would come pouring out of him were it easier for him to get them out.

The topic *Communication NOT Technology is What Counts* has once again given me cause to consider why it is that many people often don't listen, don't communicate with each other. Even people who have a voice and have vocabulary often find it difficult to reach out and truly interrelate with others. "Communication" has become a buzz word as this century has beheld many technological advances that have provided so many global and local opportunities to share ideas. Yet, I don't think many people actually feel comfortable communicating — *that is really sharing ideas, feelings, concerns.*

I note Audrey's comment (See page 20) about how it is often newer staff who don't take the time to stop, to listen to her. I've considered why this might be so. I'm sure it's not that consciously these people don't want to communicate. First, I believe it is simply that new caregivers are often overwhelmed being in a location where so many people have difficulty communicating. It is scary to think that one may not be able to understand what someone else is trying to say. Secondly, it takes time for new staff to get into the rhythms of a new job. Stopping to listen does take time, time a new person on the job, who is expected to finish a given set of tasks, may not feel he/she has.

People who communicate with Steven on a daily basis understand him far more easily than I do — they know him, his quirks, his needs. Sometimes it takes me an hour to understand just one or two of Steven's statements. It takes that time, that commitment from me. I am willing to make that commitment, however because I feel that Steven has a lot to teach me and us about the human spirit. His ability to cheerfully cope with such a disabling illness is incredible! One of the reasons a person in a chronic care setting, who has difficulty communicating will try to communicate is that the person has a need for something. Trying to understand that need will take time, but so will following up on the listening. It takes commitment to want to do either when time is of the essence. Perhaps it is because newer staff don't know the residents as people that a commitment to them is harder to make. Once a relationship has been established, it is much easier.

Communication is far more than spewing out series of words. Sharing ideas often involves trust, caring, commitment and plain hard work — even for those of us who speak clearly. We may often be afraid of making those commitments, but I have learned that truly listening to another person has provided me with some of the most rewarding moments of my life. Mind you, I am a shy person and still have a long way to go to communicate well. I am enjoying the learning experience. §

I Have So Much to Say!

AUDREY McGEE

My Lightwriter is a little printer that has many advantages. It's small so I can carry it on the table of my wheelchair. I find that it is often better to use than my letterboard for communicating because it saves the letters in sequence on a screen, so that if someone doesn't have a good memory they can see the letters instead. It also helps my memory, especially if the word I'm spelling is long. The Lightwriter also says the word after it's spelled. That way I can catch people's attention and communicate with those who don't see well, or can't see my letterboard or Lightwriter window, because they're in wheelchairs. Saving the letters on the viewing screen actually helps my spelling. My spelling is much worse since I had the stroke, but I often know if I have made a mistake if I see the whole word in front of me.

Another advantage of the Lightwriter is that it has a memory. I can preprogram 24 messages and have done so, writing the things I have to say most often. My Lightwriter acts as my voice. It's much easier than rewriting the messages over and over again. I wish the memory was larger though. I want to say so much!

It seems that my Lightwriter should have solved many of my communication problems, but that is just not so. Often, the people in the hospital I live in just don't have the time to wait for me to spell everything. Sometimes, especially when I'm tired, or frustrated, or not feeling well, spelling the words is even harder — I get all mixed up. So, although the technology is there to help me, I still often lack someone to communicate with.

I belong to a Communication Group in the hospital. We are a group of some 5-6 residents who get together every Monday, under the guidance of our speech and language therapist, to discuss current issues. We all read a newspaper article and talk about it. Many of us in the group, have a very hard time communicating. We each get a chance to talk, but, of course, those who have less difficulty communicating always get to say more! I do enjoy this opportunity to think about and discuss many interesting topics.

Sometimes it seems that when I most need to communicate something, everyone around me is in a rush. Some people, especially the newer staff, don't seem to ever want to listen. Fortunately, there are not many people like that around. My Lightwriter has a beeper on it. I try to use it to draw attention to myself, but sometimes no one stops. There are only a few people in the hospital who I know will always take the time to listen. When I need help I often go and search them out. These people always take the time and somehow seem to understand and be ready to help. They seem to understand me more than the others. I'm not sure why. They really listen! They take the little extra time I need.

I find my lack of ability to communicate fluently very frustrating. I want to say so much. It's so hard now. I do just sit and think a lot. It is harder for me to express myself and find the right words for my thoughts. Sometimes I get very depressed about it. Practice has made it easier for me to communicate. I have been writing a book, but the volunteer who was helping me with it hurt her leg and has not been able to come in to help me. Everything is in limbo. I would like to finish it very much. It's hard to always be dependent on others.

Technology certainly does help me to communicate, but it doesn't make much difference if no one is listening.

§

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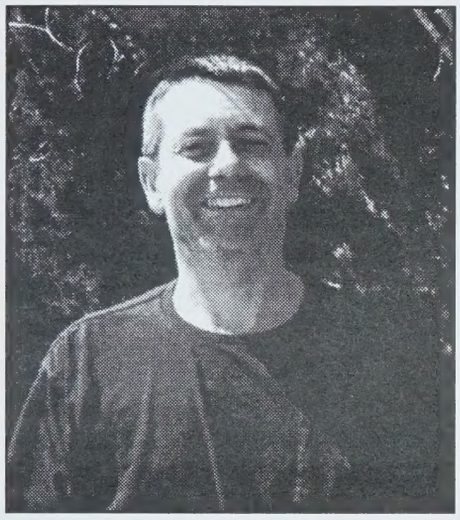
GEORGE PIGACHE



George Pigache

You can now buy a car with wonderful options. If you spend enough money, your car will do all your map reading and get you to your destination. There are however, two thoughts which spring to mind. If you are too dumb to read a map, should you be driving. If you can read a map, then why spend the considerable amount of money for this option anyway. It will take you longer to earn the money for it, than it would to read your own map. So who is in control anyway — us or it?

It's very easy to become seduced by the power of technology. This applies as much to someone buying or designing a dishwasher as it does to someone buying or designing a piece of AAC. They look so shiny and if you get all the options they will do everything you could possibly want. However, dishwasher manuals are usually simple with clear diagrams and everyday language. Because of this, when the options break down or you decide they are of no use, it is easy to choose "Normal Wash" and leave it at that. This is far from the case with most manuals which accompany computers or their software. I believe that manufacturers see the role of the clinician as the person who chooses or recommends the equipment for the client, and then trains them to use it. There are problems in this approach. It is very hard for one person to be aware of everything out there and the responsibility for picking out equipment should be that of the user. Do we let our mechanic chose the car for us when he or she has such little knowledge of our daily life and dreams? As for manuals, manufacturers need to get together and create a universal language for the aspects of their product rather than thinking up a cute name for a common function to make their idea seem unique, and everyone else's life difficult.

The user or the user's family sees the 'hi tech' equipment as being designed to solve their communication problems. The designer or manufacturer sees their product as a piece of equipment which will fill a specific need and make a profit for them. Thus you have a consumer needing ubiquitous technology but often seduced by unnecessary and complicated options, and the designer seduced by the power to upgrade and upgrade and upgrade. At present the winners seem to be the producers and distributors, and the losers the consumers and their clinicians. Adding insult to injury, even if the clinicians and consumers begin to master equipment, the upgraded version comes along with greater sophistication and greater system requirements.

Giving consumers more control and responsibility for making appropriate choices in equipment does not mean that clinicians do not have a role to play. Even before the first whiff of technology, there must be a lot of communication between the client and the clinician. This is the time for the why's and the what's, not the how's of communication. This is where the clinician could play a crucial role as a teacher. Persons wishing for the communication to occur must know why they want it. Until they know why they want it they will never become an initiator, and until the clinician knows why, he or she will never become a facilitator. I will never forget sitting with a nonverbal student trying to work out how best to lay out his communication board so he could ask to go to the washroom. Everyone was becoming more and more frustrated until we found out why he wanted to communicate so desperately. He was just about to turn sixteen and decided to refuse to take medication needed to slow his cystic fibrosis from killing him. The 'why' of why he wanted to communicate was that he wanted to talk about his death not his washroom. When we knew this, we could deal with 'what' he wanted to say. I need to pause my ramblings at this point to stress that I have seen

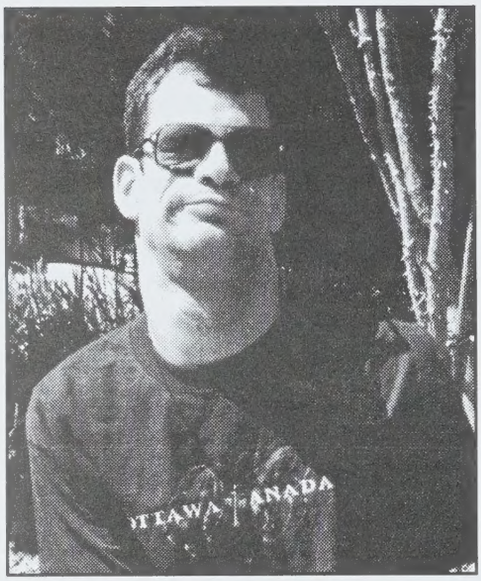
technology help people accomplish amazing things. It has given people the power to communicate at a high intellectual level, and it has enabled people to provide for their basic needs. It is the area in the middle where most users live, where it seems to be at its weakest. For the people, like the majority of us, who want to go to the movies or buy a shirt, technology is either too complicated, or too simple and restrictive to help. I think that this has become a problem because people don't design it for those with learning disabilities or people who do not have a high level of literacy

Parents of consumers, or consumers are often led to believe that technology can produce communication. In fact the reverse is the case. Until persons see a reason why they need to communicate, they will not work at initiating it. This is what produces communication and this is the point at which technology becomes a vital tool. Clinicians should not approach a client with a picture of possibilities in their minds. Rather they should help their clients pinpoint strengths and weaknesses so that they can go shopping for what they need. The most important things you learn about are the things you can go on to do independently. The levels at which we can communicate cannot be fixed by technology, but knowledge of our communication strengths can help us fix on the type of technology we need. §

PAUL'S PULPIT

Using The Grassroots of Language

PAUL MARSHALL



Paul Marshal

Before I go into the theme of this issue of ***Communicating Together****, I want to welcome you to our new section, Paul's Pulpit. It is just a renaming from Paul's Place to Paul's Pulpit. I am sorry you have to put up with the same writer. As you know most of my columns sway to a spiritual point of view. I guess my coeditors weren't too scared to give me a pulpit to talk from. Maybe they will have second thoughts in a few months, because NOW I have my pulpit! I am hoping to get people involved in my articles in the future. If you want to correspond with me I welcome your ideas and/or thoughts. My snail mail address is:*

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Communication is the most vital source we have to interact with our world. A baby cries, a bird sings out, and the wind blows through the trees. These sounds are the lowest level of language. Languages are made up of sounds to which we put meaning. We use language to express our emotions, thoughts, questions and needs. The English language is made up of many thousands of words but most of us just use a few hundred of the most everyday words. This is what I call the grassroots of language. Most people just don't use formal wording in their daily use of any language. The point that I want to make here is, just because there are thousands of words, we don't have to use all of them. The same goes for speech output devices. Sometimes the latest, greatest devices are not the best for your needs. Just know your needs and don't get trapped into thinking you must have the most up-to-date machine.

AAC (Augmentative and Alternative Communication) has numerous different forms. They include body language, spelling things out in the air to the state-of-the-art technology that we have at our finger tips today. I, along with others I am sure, am deeply concerned with the movement of thinking that we are seeing today. There is a big push to get people on a technological device as soon as possible. I question if we are getting talked into purchasing devices without really thinking about the language and social development of individuals. I have heard and been

told of many an individual's sentences or statements being programmed into their voice output device and the person not really knowing the right and the wrong settings in which to use that sentence(s). The first question that pops up in my mind when I hear this happening is, how many of these sentences are preprogrammed, and how many reflect the individual's own thoughts? My second question is where are we failing in teaching our AAC consumers the proper skills with their speech output devices as to how to interact correctly with people. I hope we don't just go through the motions of giving out devices without much training. I am not talking about the words or sentences which are programmed into the devices but I am talking about the training that is vital to provide to the consumer so that he/she can become a good communicator. I believe there is a place for technology. At the same time I believe there are places where technology acts in a negative rather than a positive way.

My life's work depends on technology. I maintain four different websites and I am always sending/receiving e-mail messages. My life and lifestyle would be extremely different without my technical equipment. But technology can't or shouldn't ever touch who I am as a person. So like Nola, I am not against technology, but I agree with Nola that there is a mentality that we have today which is pretty scary! Technology is just a brainless tool that we are allowed to use to improve parts of our life. Technology is nothing more than a hammer and a box of nails. If you learn how to use them correctly, you can build a bird house or a large house, but if you don't you are probably going to hurt yourself. We don't teach sixteen-year-olds how to drive by sitting them in a big transport truck and handing them the keys and saying, "OK, just drive". We sit them in a car and sit beside them to train them. Yet, we expect a person who is nonspeaking to know the basics of good communication, when she or he doesn't have the opportunity to develop language naturally. Sure we hear and understand the language around us. When it comes to using it ourselves, however, I believe it is harder for us, as AAC users, to master the fine points of language and communication.

Technology can't move, talk, laugh, cry, enjoy or produce life better for us. At the same time technology can *help* us if we learn how to handle it properly.

My old alphabet board is an ongoing joke because it looks so bad, but it goes with me everywhere. It has been on old farm tractors, boats, planes, my bike, in board rooms and in churches. It would be extremely hard to live without my low tech alphabet board because when we get right down to it, my old out-of-date alphabet board is at the grassroots language level.

True communication is NOT wrapped or package in any technical device. True communication and a good communicator is a person that works at the grassroots level of language while they are using technology.

§

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Communicating Together was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn.* Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

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Norman Alm and Kate Ellis, communicating together.

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